



# May 2021 COVID-19 Community Check-in

# SURVEY

FOR THE AUTISM  
AND DD/ID COMMUNITY



YOUR VALUABLE  
INSIGHT IS WANTED



## Demographics

### Distributed electronically

Survey May 7 – May 21,  
2021.

### # of Participants

6,768 survey  
participants

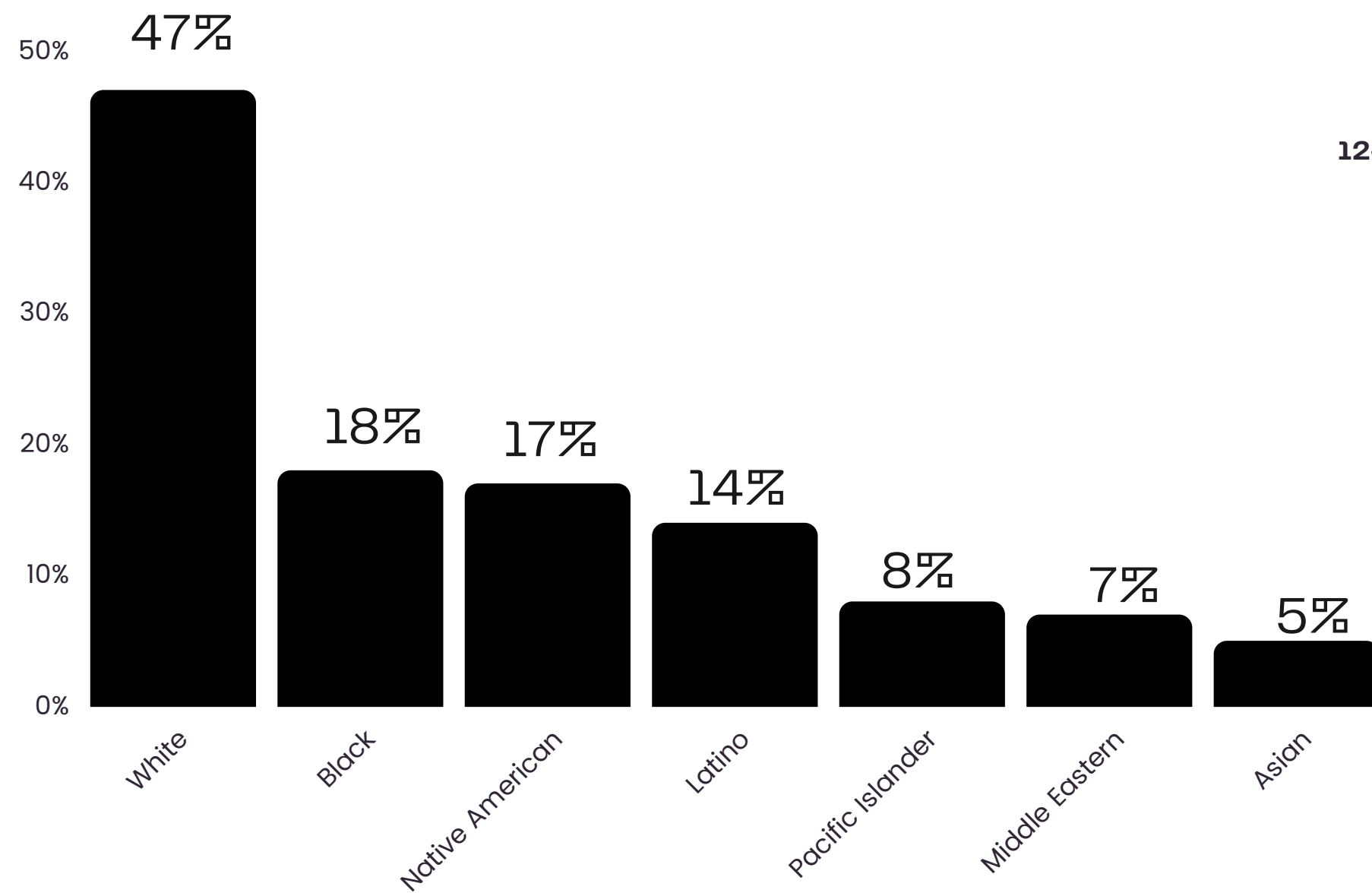
### Geographic Region

Throughout the  
United States.

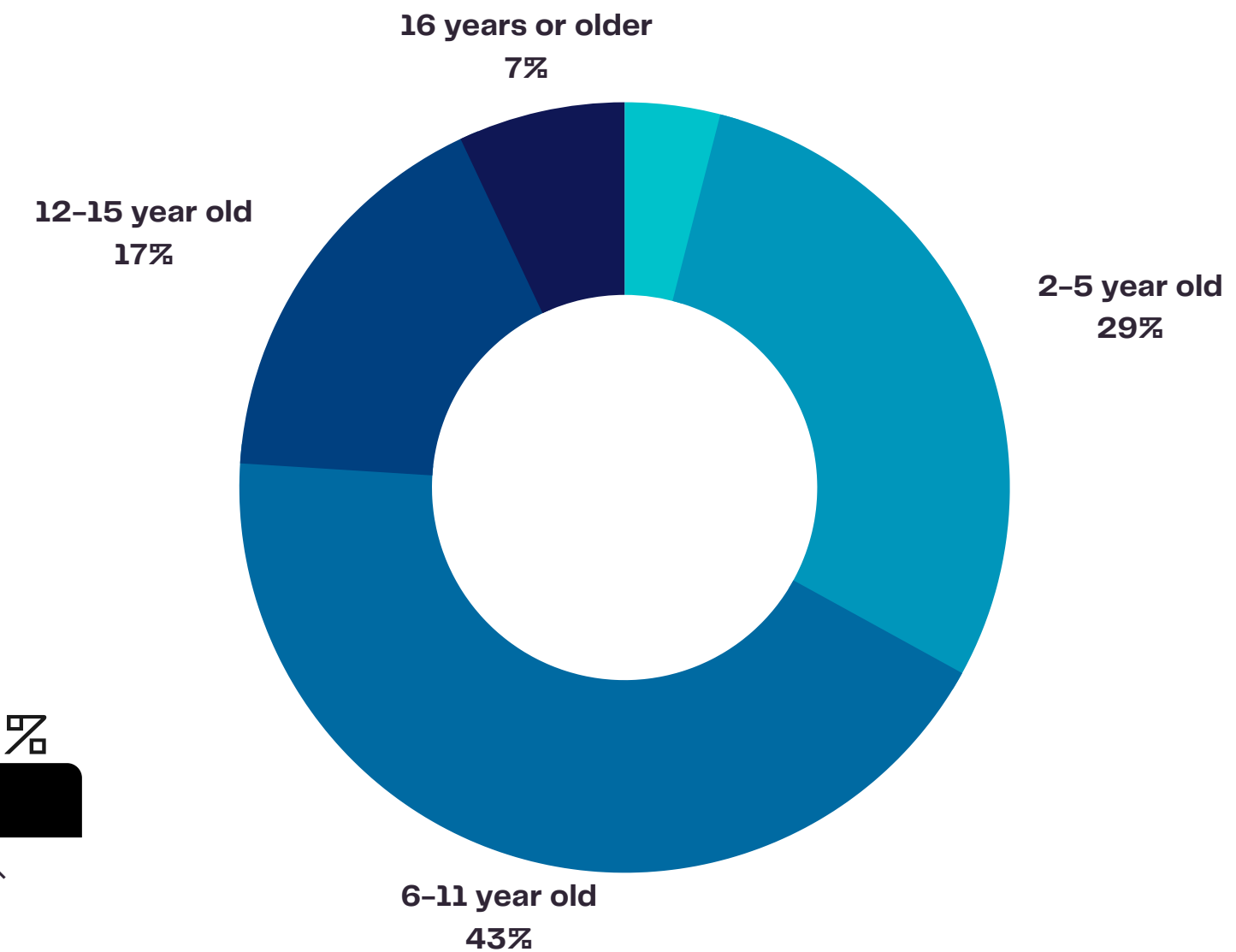
# Demographics

This survey was distributed online and had 6,768 participants throughout the United States.

## Racial/Ethnic Demographics



## Age of Person with Autism/DD







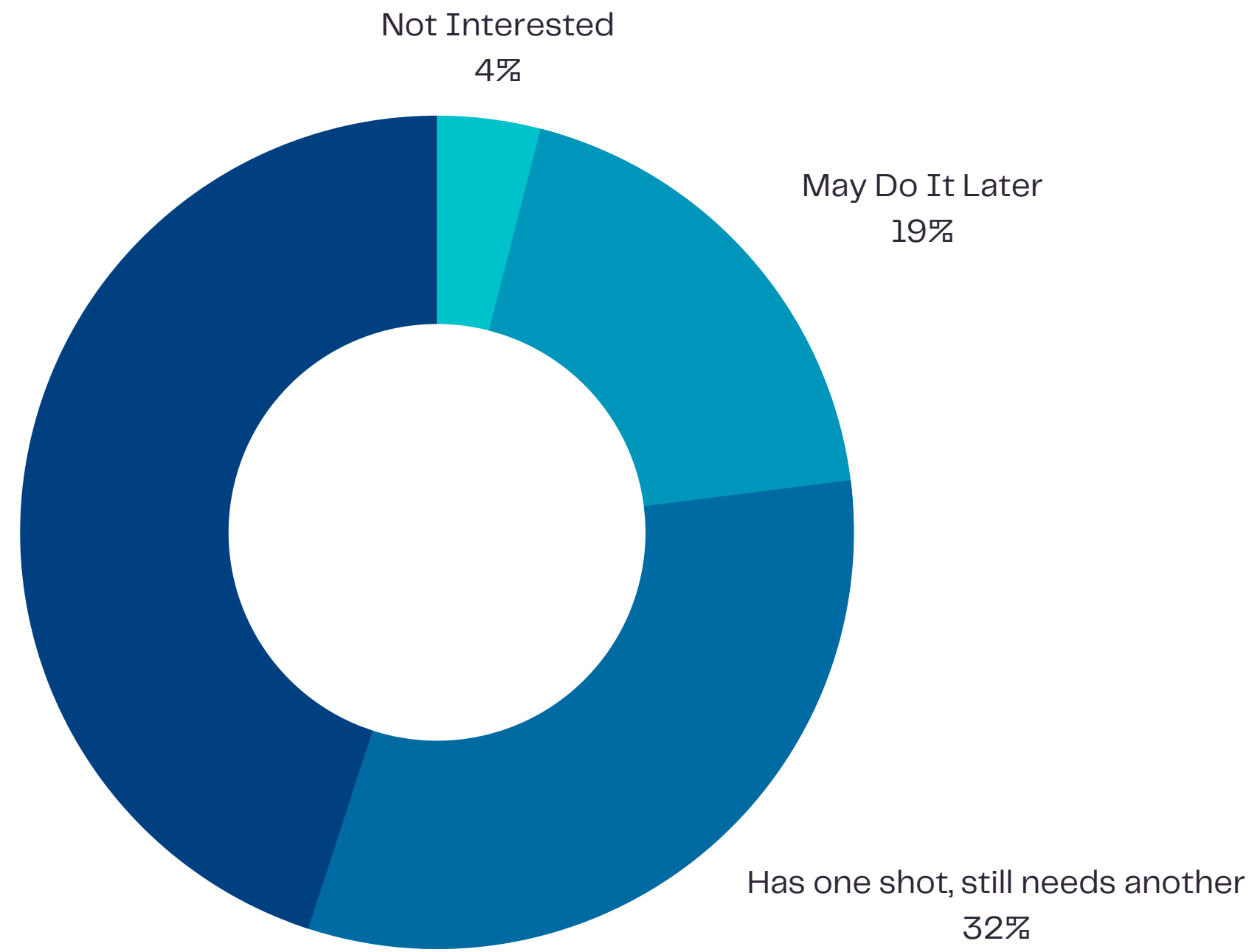
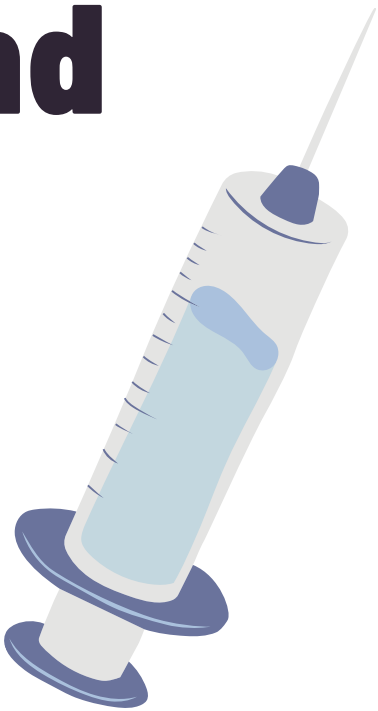
# VACCINES 77%

**of individuals 16 years  
and older with I/DD  
have had at least one  
dose of vaccine as of  
May 2021**

414 SURVEY RESPONDENTS



# Vaccination Status of 16 Years and Older with I/DD: May 2021

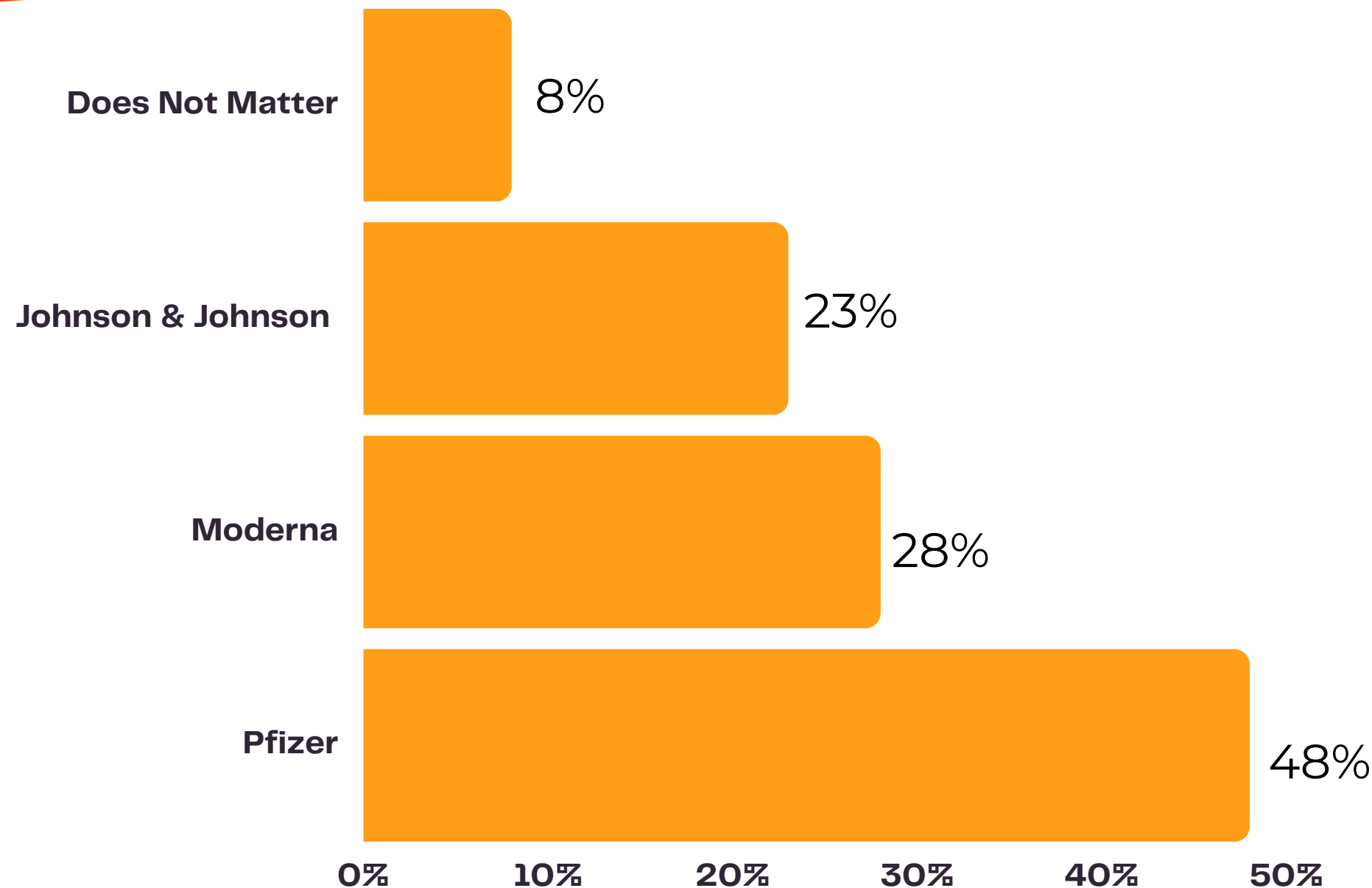
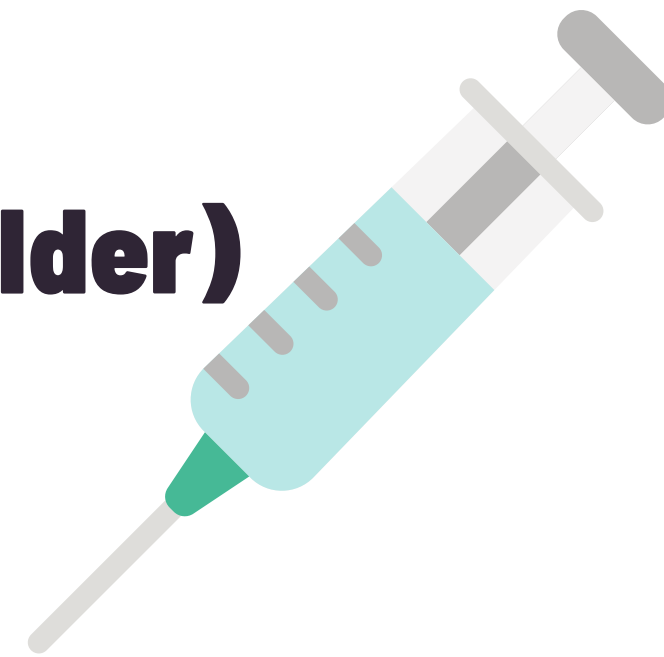


For this population, the survey showed that fully vaccinated individuals were similar to the California vaccination rate as of May 14th of 48% fully vaccinated. However, the number of people who had one shot was double that of the typical California population of 15% partially vaccinated.

More data needs to be taken to determine if this population has found barriers to getting a second shot ,or simply the timing of the survey

414 SURVEY RESPONDENTS

# Which vaccine do you prefer (16 years and older)



401 SURVEY RESPONDENTS

**The Johnson and Johnson vaccine had been popular with the I/DD community before it was paused because of reported health issues.**

**The survey looked to see which vaccine was the preferred which was Pfizer by almost double the amount of Moderna or Johnson & Johnson.**



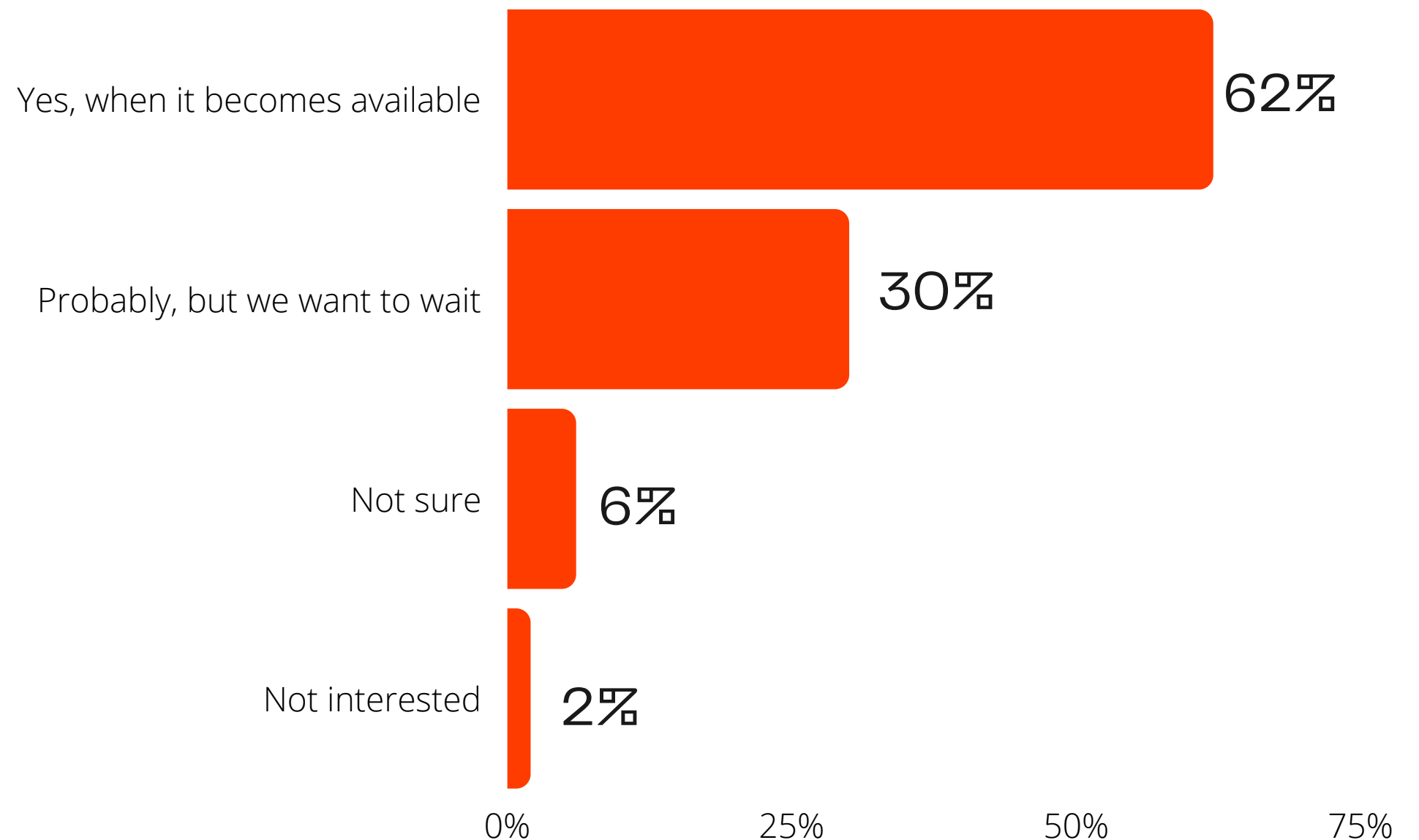
# Attitudes on Vaccines for Children 2-15 Years



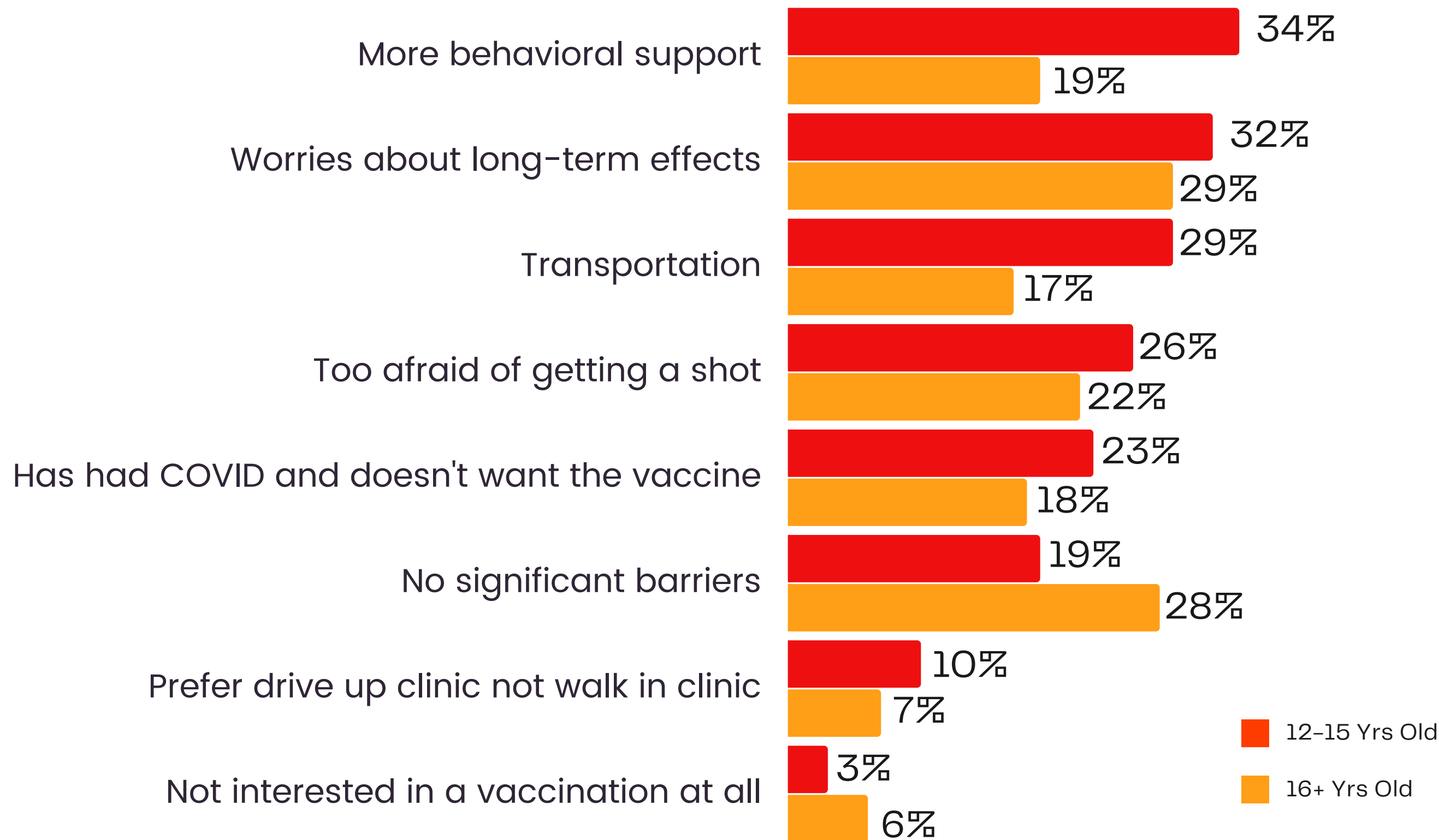
**This survey was taken before the vaccine for children ages 2-15 years was available. We asked how likely would the family be to vaccinate. Sixty-two percent (62%) of families said right away with another (30%) were likely to vaccinate.**

5982 Survey Participants

## Will You Vaccinate Your Child 2-15 Years When It Becomes Available



# Helpful Support to Access COVID Vaccinations for the Autism and DD Community



1128 survey participants ages 12-15;  
453 survey participants 16 and older

**This survey was taken before the vaccine for children ages 2-15 years was available. We asked how likely would the family be to vaccinate. Sixty-two percent (62%) of families said right away with another (30%) were likely to vaccinate.**

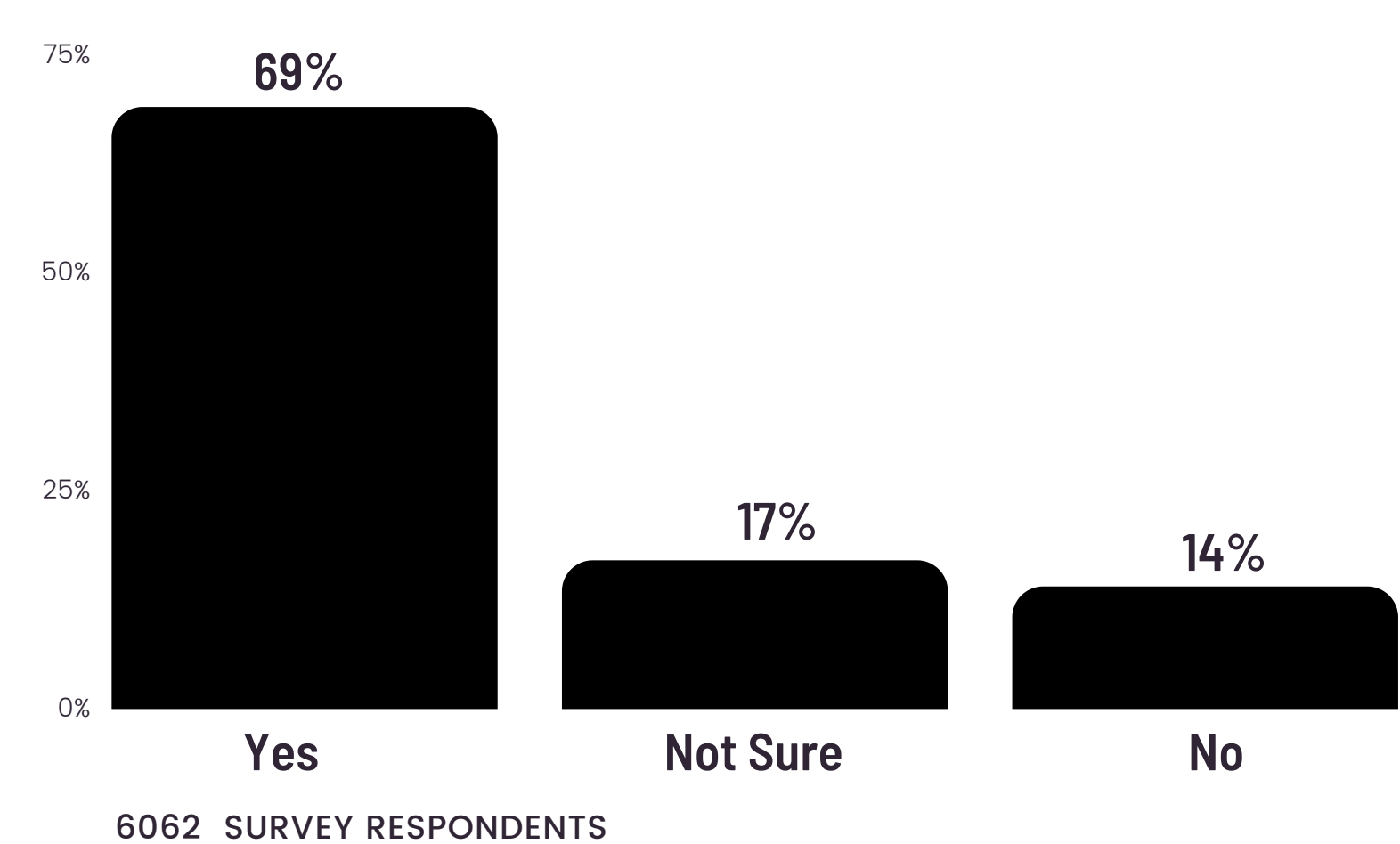


# Wearing Masks

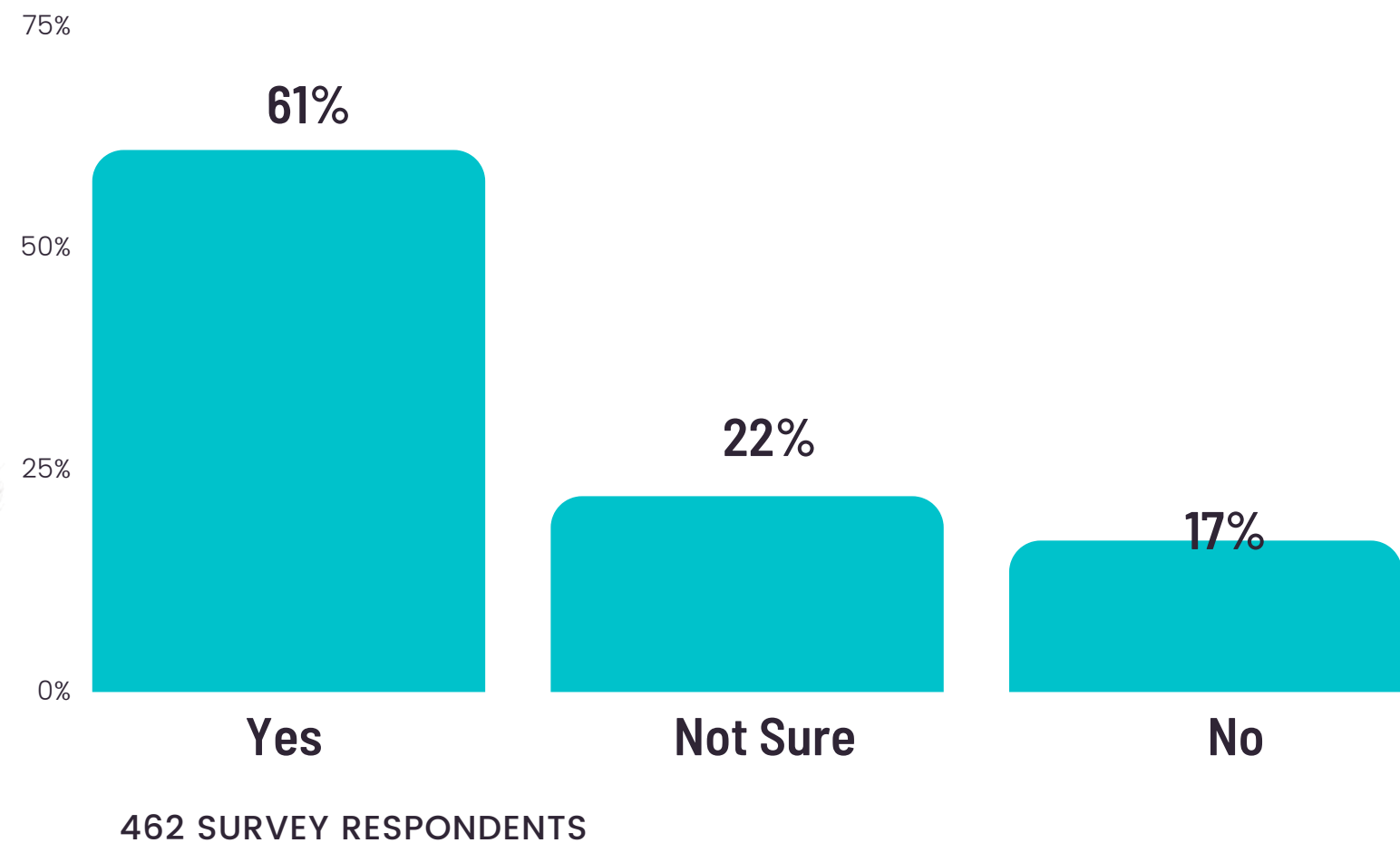
**1 out 7 children and 1 out of 6 teens/adults with Autism can not wear a mask for 90 min**

This is a decrease from May 2020 where 1 out of 4 individuals could not tolerate a mask (Autism Society of California May 2020).

Ages 2-15 Who Can Wear a Mask for at Least 90 Minutes



Ages 16 and Older Who Can Wear a Mask for at Least 90 Minutes







# RE-INTGRATION

**As of May 2021, the setting that 30-40% of the families preferred was indoor or outdoor with a mask.**

6446 SURVEY RESPONDENTS

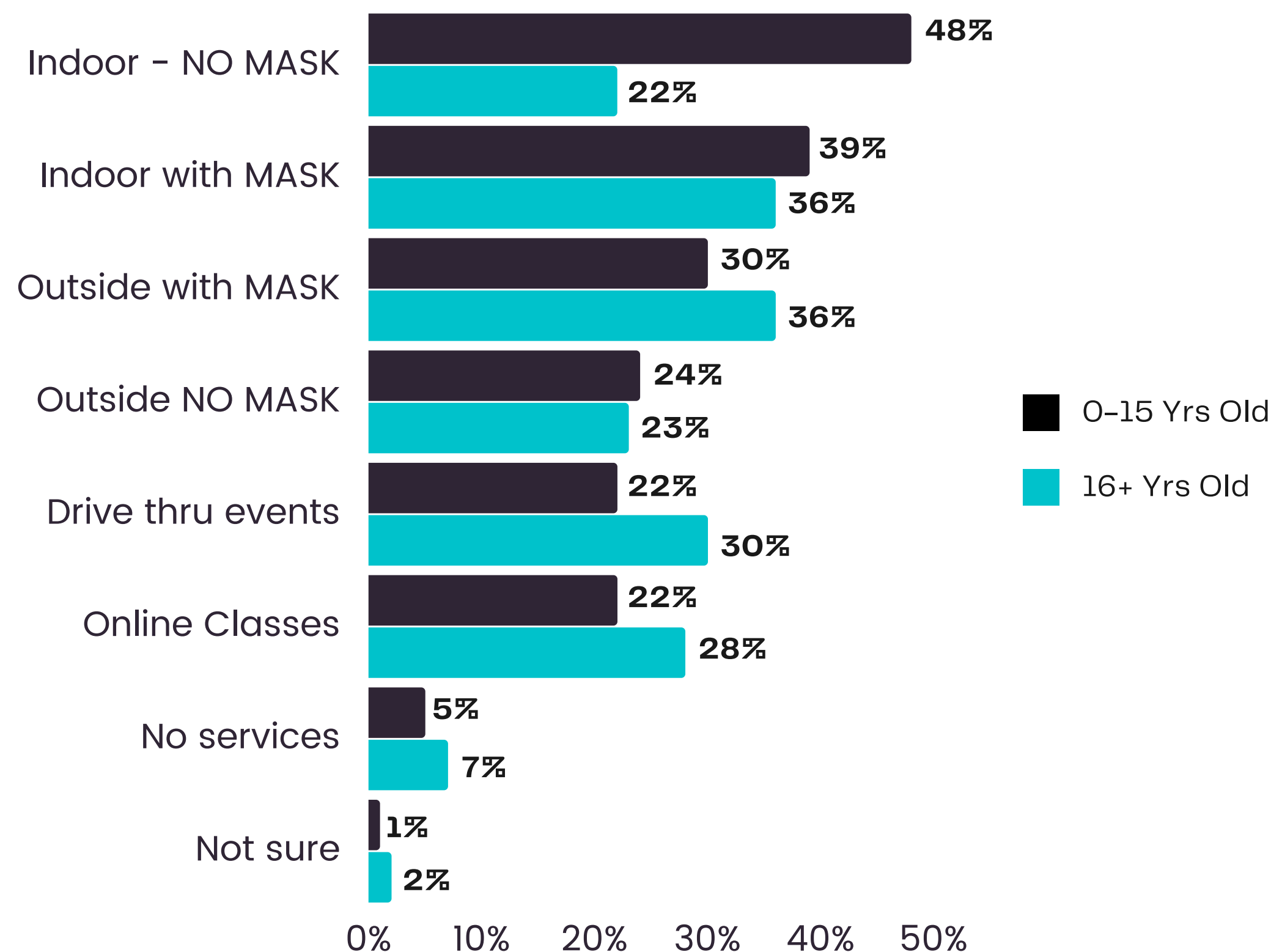


As of May 2021, families, businesses and non-profits are looking at re-integration into community events.

The Survey showed a slight difference between the age groups. The biggest discrepancy was indoor events. The most requested setting for families with younger children was inside with no mask (48%) compared to 22% of families with a loved one older than 16 years old.

As of May 2021, the setting that 30-40% of the families preferred was indoor or outdoor with a mask.

## What Type of Activity Do You Prefer Right Now?



5986 Survey participants ages 0-15 yrs; 460 ages 16 and older - multiple answers

# CRISIS

# 78%

**of families feel like  
they are in a crisis  
right now.**





# 1 OUT OF 3 FAMILIES HAVE HAD A BEHAVIORAL CRISIS IN THE LAST 3 MONTHS: MAY 2021

Behavioral aggression in children, teens, and adults with autism is a serious issue for a family. Handling an aggressive crisis can be distressing and exhausting for everyone. Changes in routines, lack of access to services and therapies have created a new level of stress for families.

The May 2020 Autism Society of California showed that 1 out of 4 families were reporting aggressive behavior. A year later 1 out of 3 families are reporting aggressive behavior.

Compounding this issue is that often there is no clear path to a multi-disciplinary team who can determine if behaviors are rooted in a medical, psychological, communicative or environmental cause.

Has your loved one had a behavior crisis in the last 3 months - all ages?

**37% Frequent, serious self-injury**

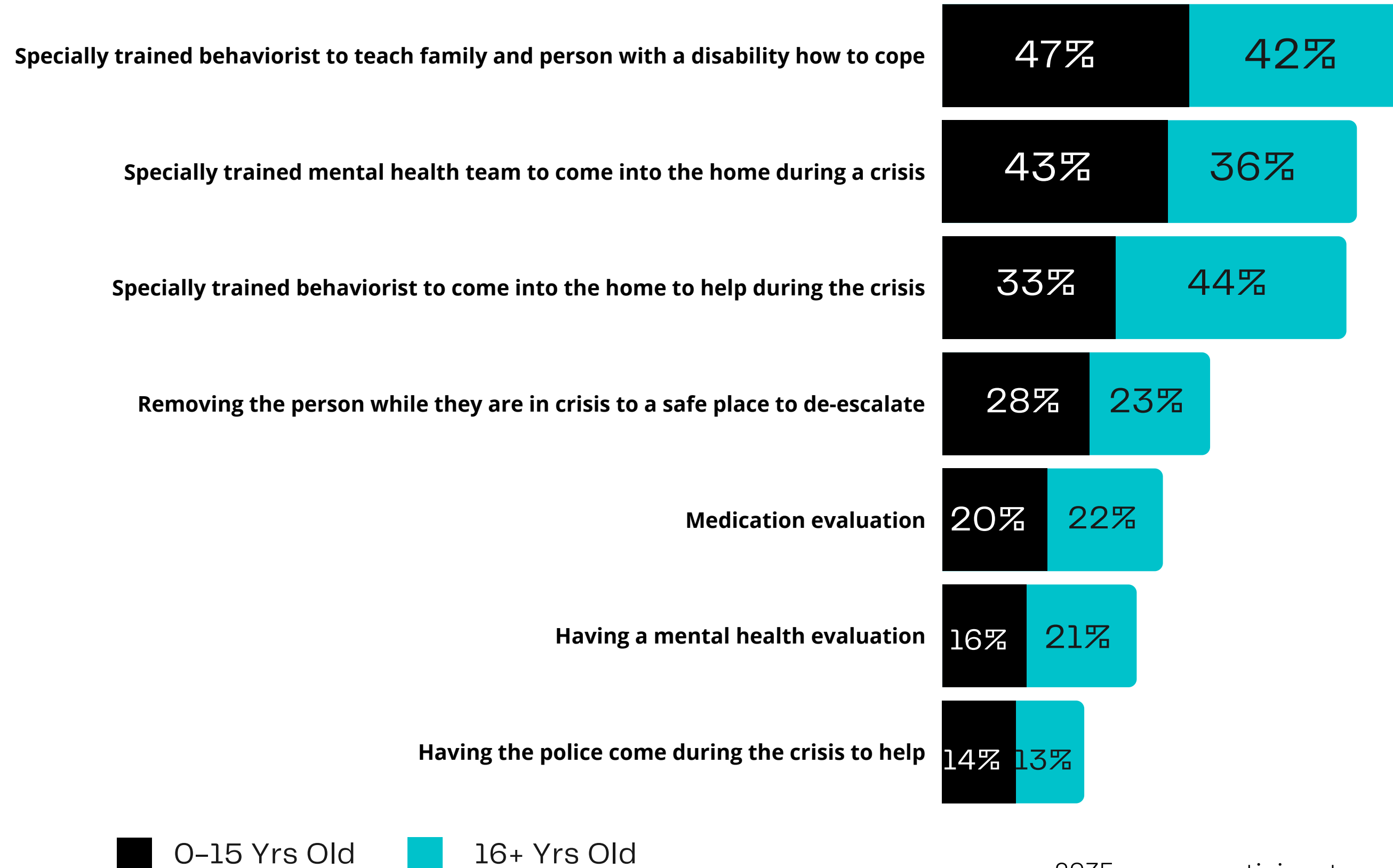
**35% Repeated physical aggression**

**27% Frequent, Serious and persistent sleep disturbance**

**24% Destroys property**

**19% Verbal aggression and threatening behavior**

# What kind of crisis response do you think would help you the most during a behavioral crisis?



When asked what kind of help families are seeking during a behavioral crisis, almost half the families asked for a specially trained behaviorist to teach the family and person how to cope (47% ages 0-15 years, 42% ages 16 years and older). The next most requested help families requested is having a specially trained mental health team.

This highlights co-occurring conditions often exacerbate core ASD symptoms. One study showed that 95% of youth on the spectrum had at least three comorbid disorders and 75% had at least five. It is apparent that individuals on the spectrum have higher levels of comorbidity, especially psychiatric and physical conditions, compared to their neurotypical peers (Journal of Autism and Developmental Disorders, 40, pages 1361-1370, 2010).



# FOR MORE INFORMATION

Autism Society Inland Empire



[ieautism.org](http://ieautism.org)